The fetus as a patient: different positions on the same concept

El feto como paciente: diferentes posturas sobre un mismo concepto

Milagros Ma. de las Mercedes Moreno D'Anna,* Gustavo Páez**

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Abstract

Congenital anatomical malformations, such as genetic disorders, are a current and frequent cause of eugenic abortion in countries where abortion is decriminalized and/or legalized. Diagnostic and therapeutic fetal medicine, including intrauterine fetal surgery, has placed the fetus as a new patient in the universe of biomedical science. To state that the fetus is a patient would mean recognizing that it is a person. To know whether a fetus is a patient or not, it must be established whether it has an independent moral status. In this article we will analyze three positions on the consideration of the fetus as a patient.

Keywords: fetus, person, patient, fetal surgery, eugenic abortion, personalism, principlism.

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* Universidad Austral, School of Biomedical Sciences, Department of Bioethics. Argentina. Email: mdmoreno@austral.edu.ar
https://orcid.org/0000-0001-8647-2591
** Universidad Austral, School of Biomedical Sciences, Department of Bioethics. Argentina. Email: gpaez@austral.edu.ar https://orcid.org/0000-0003-3862-7426
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1. Introduction

Congenital anatomical malformations such as genetic disorders are a current and frequent cause of eugenic abortion in countries where abortion is decriminalized and/or legalized. In Spain, in 1985 abortion was already approved when «it is presumed that the fetus will be born with serious physical or psychological defects, provided that the abortion is performed within the first twenty-two weeks of gestation...» (1).

With the advent of different prenatal diagnostic techniques, it has been possible to evaluate the unborn child, determine any disease and establish the prognosis (2). This great advance in science has allowed two antagonistic actions. One consists of the benefit of early diagnosis of pathologies that, if treated in time and in an adequate manner, can save the life of the unborn child and/or improve its postnatal quality of life, being an example of treatment fetal surgery. But it has also allowed the sensitivity to the equal dignity of all human beings to be largely lost, causing intolerance to the birth of people with a congenital disease or who may have some kind of disability (1) or, at least, *the right to choose* whether to continue with the life of the fetus (3). As Best states, many times the mentality that guides this technique is oriented to «assure» that the unborn child will not have any congenital defect (4), originating a kind of pressure, in case the fetus presents some disability, to be «discarded». In many cases, even mothers who decide to go ahead with their pregnancy tend to feel discriminated against (5).

All this is a consequence of the utilitarian premise that considers that the poor quality of life of a person, as a consequence of congenital disorders, increases the «total amount of damage» (6). Nuccetelli (2017) responds to that presupposition with concrete cases of patients with myelomeningocele, who do not consider that they have poor quality of life. In the same vein, although more broadly, Campbell and Stramondo deny that disability is equivalent to poor quality of life (7).

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Diagnostic and therapeutic fetal medicine, including intrauterine fetal surgery, has placed the fetus as a new patient in the universe of biomedical science. It is a means to care for the fetus from the initial moments of its existence and to provide it with a better quality of life, without putting its mother at a disproportionate risk.

In this article, after a brief historical review of the main milestones that gave rise to fetal medicine and intrauterine fetal surgery, we will focus on the consideration of the fetus as a patient. As will be seen below, we will analyze the three positions that currently exist on this subject.

2. Fetal surgery

Fetal surgery is an invasive procedure performed on a fetus in utero to help improve long-term therapy for children with specific congenital defects. This technique is used because these defects often worsen as the fetus develops. Fetal surgery is performed by a team of experts who focus on treating and improving conditions before birth (8).

In 1884, Cohnstein and Zuntz reported the first non-human fetal surgery, but in the 1940s techniques were developed that allowed a rat fetus to be removed from the uterus, surgically treated, and successfully returned to the uterus, continuing the pregnancy (9). The first report of human amniocentesis in the literature was published by Lambl in 1881, in Germany, for the treatment of polyhydramnios (10).

In 1952, Bevis used amniocentesis to determine the severity of Rh incompatibility erythroblastosis (10). Fuchs and Riis used this procedure for sex determination and hereditary diseases.

In 1965, Liley implemented intrauterine transfusion to cure Rh incompatibility erythroblastosis (9). This methodology was made safer by the use of ultrasound (10), which was first described as a method for obstetric evaluation in 1968 (9). When it became possi-

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ble to perform relatively noninvasive fetal transfusion using ultrasound guidance, efforts to access the fetus through open fetal surgery ceased (9).

In 1972, the work of Liggins and Howie demonstrated a more than 50% reduction in cases of hyaline membrane in live-born preterm infants at least 24 hours after inducing pulmonary maturity with betamethasone (11). In 1974, the first fetal visualization by fetoscopy was performed at Yale University, initially oriented to direct diagnosis, or to obtain biopsies (11). In 1975, Benzie and Doran used a fetoscope to visualize intrauterine contents prior to saline abortion (10).

In 1981, fetal surgery went from being a diagnostic tool to a therapeutic tool in experimental models in primates. Michejda and Hodgen devised what they called HAVIT (Hydrocephalic Antenatal Vent for Intrauterine Treatment) (10). It was proven that, with the placement of ventricular shunts in these hydrocephalic primates, there was greater survival to delivery, better motor skills and postnatal weight progress. These primate models were able to identify that the use of inhaled anesthetics was a risk factor that decreased uterine activity (10). Similarly, it was revealed that metal staples decreased maternal fertility by 50%, but it was also shown that future pregnancies were possible after fetal surgery (92.6%) (10).

The first open maternal-fetal surgery reported in humans was in 1982 by Dr. Harrison (12). A vesicostomy was performed on a fetus with bilateral congenital hydronephrosis. Since that time the field of fetal therapy has gained importance and consideration of the fetus as a patient (12).

Despite several failures in animal trials, Dr. Michael Harrison continued to conduct research on fetal surgery in lambs and monkeys, refining the criteria for different fetal interventions (10).

In 1982, various professionals (perinatologists, obstetrician-gynecologists, ultrasound experts, pediatricians, surgeons, bioethicists, physiologists) from a dozen institutions in five countries met

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to discuss the emerging field of fetal therapies (11). Thus, the International Society for Fetal Medicine and Surgery was created, which established the first basic criteria for performing fetal surgery. These are listed below:

1. Anatomical malformations suitable for in utero treatment are simple structural defects that interfere with organ development, but which may allow normal fetal development to continue if corrected.

2. The fetus must be unique, with no additional structural or genetic abnormalities.

3. The natural history of the fetal defect and disease must be known, with intervention justified only if there is a reasonable likelihood of benefit.

4. A careful serial evaluation of the anatomy and function of the organ should be performed before surgery is considered, to exclude fetuses that are mildly enough affected that they can wait for postnatal therapy, as well as fetuses so severely affected that they cannot be saved.

5. The family should be counseled about the risks and benefits and agree to treatment, including long-term follow-up.

6. A multidisciplinary team including a maternal medicine specialist experienced in prenatal diagnosis, a pediatric surgeon, and a neonatologist should agree on the treatment plan.

7. There should be access to a high-risk level III obstetric unit and a neonatal intensive care unit, as well as bioethical and psychosocial counseling.

In 1994, the team led by Dr. Rubén Quintero performed the first umbilical cord ligation through fetoscopy. In 1995, the same researcher's team performed the first fetal cystoscopy to treat bladder obstruction caused by a valve in the posterior urethra, using laser (11).

With the new millennium, important publications of multicenter European groups appear, such as the one led by Ian Deprest, which highlight the future potential of this surgery, and make an

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account of the progress in the main indications of that moment, especially oriented to the prevention of sequelae of pathologies not treated in the fetal stage (11), or as the randomized and controlled study MOMS of 2011, conducted in 3 American centers, which studies the benefits of fetal surgery in patients with myelomeningocele.

Since 2010, training and development centers have begun to be set up in Latin America. Some countries, such as Mexico, Chile, Brazil, Venezuela and Argentina, have published important experiences: in Querétaro, Mexico, there is the group led by Dr. Rogelio Cruz; in Chile, the one led by Dr. Yamamoto and Dr. Otayza and, in Argentina, Dr. Echegaray (11).

Recent studies have concluded that myelomeningocele surgery currently offers satisfactory results, with significant benefits for the fetus and its future life, and that the risks for the mother and the fetus are acceptable (13). Experience shows that mothers are very satisfied with the results obtained, even if the recovery after surgery has sometimes been more laborious (14).

3. The fetus as patient

One of the bioethical challenges in perinatology is the use of non-invasive and/or invasive technology that provides information on fetal health; that provides guidance for therapeutic management and generates maternal-fetal well-being (15). The maternal dependence of the fetus and the need to pass through the mother's body for diagnostic procedures and treatments means that, although infrequent, there may be potential conflicts that call into question the status of the fetus as a patient (16). Knowing how advances in prenatal diagnosis directly influence the care of the pregnant woman, places the fetus as a patient, by establishing communication with him to know his state of health. All this will make it possible

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to generate an ethical and social medical commitment, which tends to avoid aggressive interventions on the mother and fetus with respect for their human dignity (15). Because of the existing risks, it can be considered that it is not possible to speak of a medical obligation to always intervene; we consider that this position would also be erroneous and extreme (17).

The first component of the proposed comprehensive approach to the ethical analysis of fetal surgery is the ethical concept of the *fetus as a patient*. This concept was employed by Chervenak and McCullough, in proposing an ethical framework for perinatal medicine (18). These authors consider that the fetus can be considered a patient, although they do not attribute an independent moral status to it. They argue that there is a link between the fetus and its future moral status.

That is to say, to state that the fetus is a patient would mean recognizing that the fetus is a person. The various positions that have been taken throughout the history of medicine show that not everyone would support this assertion (19).

In 1948, the Universal Declaration of Human Rights established in its 3rd article: «Everyone has the right to life, liberty and security of person» (20). This is a clear fact in the defense of the right of every person to life. The current discussion revolves around when a human being begins to be a person.

The concept of the fetus as a patient can be explained from three philosophical visions or foundations, on the concept of person and the obligations that must be had towards it (moral status). To know whether a fetus is a patient or not, it must be established whether the fetus has an independent moral status. This implies that the characteristics possessed by the fetus are independent of the mother or any other factor and that, therefore, they generate obligations towards the fetus on the part of the mother and her physician (21). We will analyze three positions that use different rationales to determine whether the fetus is a patient.

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a) Ontological foundation

Ontological personalist anthropology, which defends the substantiality of the person and the substantiality of the spiritual soul (22), makes it possible to explain why man is a person from the moment of conception, or why man is a person even if he is in a situation of lesser physical, moral or intellectual integrity (15). This would be the case of embryos and fetuses, with or without malformations.

The classical philosophers derived the dignity of the human person not only from the intellectuality or rationality of man's nature, or from his self-awareness, but also from his subsistence dimension. *«Being» is affirmed principally in substance; a substance is properly «a being»; that is, that which exists in itself or by itself, or that which subsists by itself and not in another*. Only the subsistent individual possessing rational nature can be called a person (15) and, as a person, he has rights, independently of the functionality or exercise of rationality that he may possess.

The ontological foundation of the person does not reduce the person to his specific acts (present or future), but accepts the existence of the person, as a substance, when his acts do not yet reflect all his capacities, either due to lack of development, as would be the embryo, or when his already developed capacities cannot express themselves, due to a physical or intellectual disability that occurs accidentally (15). For this reason, he considers that the fetus is a patient from the very moment it begins to exist, after the fusion of the male and female gametes.

Moratalla (1) agrees with this ontological foundation, and affirms that perinatal medicine considers the fetus as a patient, who can not only be diagnosed better and more accurately, but also treated. The fetus as a patient is in phases of special fragility and vulnerability, thus needing very specialized care. Prenatal therapy seeks a benefit for the unborn and for the intervention to be low risk. It is commonly accepted that, in order to offer any procedure in favor

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of prenatal health or welfare, the probability of cure or potential benefits, the safety of the intervention, based on experimental animal models, and the assessment of the risks on the life and health of the mother must be assured. Logically, her consent is required after clear and objective information on the risks and benefits for her and for the child (1). These conditions are very well expressed in the IFMSS criteria (criteria for the performance of fetal surgery created by the founders of the International Society for Fetal Medicine and Surgery in 1982).

The ontological foundation is based on the information offered by biology, which allows us to distinguish a new being from the genetic information of the zygote. From that moment on, there is a new body (empirically verifiable), which possesses its own identity, continues its own life cycle (assuming all necessary and sufficient conditions) under its own autonomous control, which builds itself in a highly coordinated process, dictating to itself the directions of growth, according to the program of its own genome (23). This zygote will pass, without interruption, through the various stages until it reaches an adult individual. This common identity, maintained throughout development, is what leads us to affirm that the fetus is a person (24). From this observation arises the recognition of an intrinsic dignity of the fetus, which makes it worthy of human rights (25) throughout its existence.

Moratalla describes the «molecular dialogue» between the newly conceived embryo and its mother: *As it travels the path to the uterus, the newly conceived embryo releases interleukin molecules, which are received by specific receptors in the mother's fallopian tubes. In response, the fallopian tubes produce several substances. The so-called growth factors, which allow embryonic development. Survival factors (inhibitors of apoptosis or programmed cell death), which inject the vitality that the embryo needs because, during the first 5 days, it has no more energy than that stored in the ovum. The* LIF *factor, by having receptors in the cells of the trophoblast (the envelope) of the embryo, makes it possible for its cells to form part of the immune system at this stage of gestation; so that the trophoblast begins to act as the skin of the embryo* (26).

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As we will see below, other positions deny this continuity of the human being, affirming that the person can only be recognized at certain moments of its existence. For these authors, the person would be identified with the manifestations of intellectual capacity, especially in self-reflection. Examples of this position are the authors of utilitarian orientation (27).

b) Functionalist foundation

In contrast to personalist bioethics, there are authors of functionalist currents such as Peter Singer (28), who affirm that ethics extends to all beings endowed with sensitivity: *all beings that are capable of feeling pain and pleasure are considered moral subjects.* Taking the above into account, Singer places the fetus (not the embryo) in the same moral status as an animal. He also states that it *is immoral to allow those beings whose mental capacity is less than ours to suffer.* If the fetus feels pain, it can be harmed in a moral sense. In turn, he asserts, *the embryo has no interest and, like other insentient organisms, cannot be harmed in any moral sense* (29).

Dr. Baez-Reyes, from the Instituto Nacional de Perinatología-Clínica de Especialidades de la Mujer (Mexico) (30), has a more pro-fetus stance: she defines it as a «potential person»: *the union of the sperm and the oocyte gives the potential for a fetus to become a person with morally relevant reason, and the term potential is used to describe a possibility for the fetus, which is a potential person on that path, as long as its growth is not affected.* She also asserts that the fetus, or also called a potential individual, is a different patient from already born and developed children. For this reason, she rightly affirms that sick fetuses have the moral right to be attended and treated when there is a cure, with the prior consent of the parents, being the responsibility of the health services to offer them the benefits of the medical systems, with the necessary quality and warmth. However, it assures with words typical of the current neo-language and with a concept of *human dignity* typical of those who think that there is an ontological

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leap that turns a potential individual into a developed person that, when faced with a fetus with defects or diseases incompatible with life, the latter has *the right to be treated with all respect and in accordance with the decision of the parents not to prolong its agony beyond birth, with all the burden of medical assistance and therapeutic ingratitude that will only lengthen its deteriorating and painful terminal process; also has the right to a dignified death prenatally* (28).

Chervenak and McCullough (31) can be included in this group, although they could also be included in the third (because they resort to principled concepts). They claim that the moral status of the fetus depends on whether it is reliably expected later to achieve the relatively unambiguous moral status of becoming a child and, even later, the moral status of becoming a person (29). This is arguably a «conditional» recognition. The fetus is a patient, and therefore a person, when it is reliably proven to have a chance of becoming a child (29). They argue that possessing a moral status means that others have an obligation to protect and promote the interests of that entity. They disagree with the assertion that a fetus has a moral status independent of other entities, including the pregnant woman, the physician, and the state, thus creating obligations of others toward it (29).

These authors explain that the first link between a fetus and its subsequent moral status as a child and then as a person is extrauterine viability (20). When the fetus is viable and the pregnant woman presents herself to the physician (formally caring for her pregnancy), that is when, in the view of these authors, the fetus becomes a patient (29). The second condition that makes a fetus jump ontologically to become a child and then a person is the pregnant woman's decision to continue a pre-viable pregnancy to viability and, therefore, to term (29). Consequently, ethical criteria to guide innovation in fetal surgery must take into account obligations based on beneficence for the fetal patient (adjudicated by viability and maternal decision) and obligations based on beneficence and autonomy for the pregnant woman (29). Briozzo *et al.* (16), citing

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Chervenak and McCullough, state that it is the pregnant woman who presents the fetus as a patient, although this does not automatically make it a subject of rights (16).

Dr. Sebastiani (20), with a view similar to the two previous authors, affirms that *«viability» is the first ethical «sense» that the fetus has as a patient* (20).

> Viability is not an intrinsic property of the fetus, because it must be understood biologically and technologically. It is by virtue of these two factors that the fetus can be viable and can exist outside the uterus and become a child. Both of these factors are not dependent on, nor do they exist as a function of, the autonomy of the mother. Therefore, the fetus is a patient when it reaches sufficient maturity to survive the neonatal period, either by its own means or by assisted means. Since viability depends on the place where the fetus is to be born, the concept of viability differs from place to place. The advice given to the mother for the benefit of the fetus must take into account the severity of the fetal anomalies, extreme «prematurity» and the mother's obligations. The more severe the fetal anomaly or the options of dying or being left with a permanent neurological deficit the less targeted the advice directed toward fetal benefit (20).

According to the aforementioned authors Chervenak and McCullough, and according to the criticism made by Carlos Alberto Gómez Fajardo (32), there would be situations in which there would be the paradox of a twin pregnancy with one of the fetuses sick and the other healthy, in which one of them would be a patient and the other not, justifying the selective feticide of the sick one as an action of a «therapeutic» nature, coherent with the will and interests of the mother (30).

As we have seen, the authors with a functionalist foundation occupy a wide range that goes from the denial of the fetus as a patient to a relative and conditioned recognition. They deny that the fetus has an intrinsic dignity, and some of them make its moral status dependent on its vital prognosis and the acceptance of its mother (33).

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For these authors, the determining factor is what the person can «do», and not what he «is». We find significant the position of Mills (Mills 2013), who states that certain fetuses have «potential personhood» (which cannot yet be exercised) and, therefore, are not persons (34). In our view, personhood is not in potency: it either is or it is not. What is in potency, in this case, is the possibility of exercising personal attributes.

c) Principlistic foundation

The principlist authors elaborate a moral «paradigm» for those who work in the field of health, in order to provide a practical and conceptual reference that can serve as a guide in concrete situations. This paradigm is based on the principles of autonomy, beneficence, non-maleficence and justice, interpreted in the light of two theories, mitigated utilitarianism and *prima facie* deontology (33).

An example of this type of ethical perspective is that of Dickens and Cook (35), who analyze the ethical implications of the concept of the fetus as a patient from this point of view. While they agree on beneficence and non-maleficence towards the fetus and the mother, they make the principle of maternal autonomy prevail as a way of respecting the principle of justice when there are conflicts of interest. *They argue that physicians have developed the concept of treating fetuses as if they were patients, not in order to subordinate pregnant patients to the interests of the fetus, but to guard against the significant repercussions that treatment of the pregnant woman may have on the fetus.* Dickens and Cook assert that this concept *reflects several key ethical principles, including the historical ethical principle of «do no harm» (non-maleficence); the positive duty to do good by allowing patients to exercise their right to choose in a protective manner and for the benefit of the children they intend to have (beneficence); and both as central elements of the principle concerning respect for patients* (34). This allows pregnant women to retain their autonomy, as they make informed decisions, allowing, in turn, for the protection of the most vulnerable. *Women who are*

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dependent on medical treatment and information are vulnerable, as are fetuses at risk of harm due to ill-informed medical decisions made by health care providers and their patients (34).

Dickens and Cook's view of the administration of justice recognizes the dependence of the fetus, but considers the pregnant patient on an equal footing, no longer with the fetus, but with those patients who are not pregnant (e.g., other family members). This is the basis on which British law expressly permits the option of abortion because of the effects that continuation of the pregnancy could have on the health of the children born to the pregnant woman (34).

Rodrigues Catarina *et al.* criticize Chervenak and McCullough's ethical framework for perinatal medicine (Chervenak and McCullough, 2003). They argue that, from the point of view of principlism, two principles should be taken into account: autonomy and beneficence. They understand that, above the principle of beneficence in favor of the fetus, is the principle of autonomy of the mother. This autonomy allows the pregnant woman to grant and withdraw patient status for herself and the fetus. For this reason, they consider that the moral status of the woman is superior to that of the fetus. The conclusion is that the fetus is not a patient to the same degree as its mother (36). In contrast, De Vries holds the opposite position: the beneficence of the fetus should be above the autonomy of the mother, avoiding the alleged conflict between the mother and her child, through the concept of *respect* (38).

Radic *et al.* acknowledge that there is much debate about the personal *status* of the fetus. They state that, according to the position taken on this personal status, it will depend on whether only the mother or also the fetus is considered a patient. They even acknowledge that some authors consider that the mother would be an «altruistic volunteer» and the true patient would be the fetus. For these authors, since both the mother and the fetus are intimately related, and both undergo the intervention, both should be considered patients (38).

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It can be seen that principlism presents the difficulty of the absence of an anthropology to serve as a reference. This leads to the fact that, depending on the point of view, preference is given to one principle or the other, understanding them as if one were in competition with the other (39). Moreover, both Beauchamp and Childress and their followers have moved towards a preponderance of patient autonomy, to the detriment of the principle of beneficence (40).

4. Conclusion

The ethical foundation that considers that every human being is a person and, therefore, worthy and deserving of rights from conception to natural death is based on the continuity of being, which does not vary with the stages of development or with the accidents that befall the individual. This position considers that the fetus is a person with independent moral status and, therefore, becomes another patient different from its mother. It respects the life and dignity of the fetus.

The bioethical currents that conceptualize the person and its dignity according to the functions it can fulfill, viability or the state of development in which they are, share the concept of the fetus as a patient, but its moral status will depend on a third party. In this case, it is only considered a patient if the mother presents the fetus to the physician for care. This position prefers the abortion of malformed patients as a compassionate action towards the parents and the fetus itself.

Principlism coincides with the idea of respecting the dignity of the fetus as a patient, guided by the principles of beneficence and non-maleficence, but prioritizes maternal autonomy over the aforementioned principles. For this reason, it consents to actions against the life of the unborn for what it considers a matter of jus-

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tice towards the mother, who can choose eugenic abortion as a solution. The difference observed with respect to maternal autonomy between the personalist and the principlist view is that, in the case of the former, maternal freedom is not above the life and dignity of the child, and that her autonomy is manifested by the choice of whether or not to have surgery performed through her. Her refusal is also acceptable.

Ethical views such as the functionalist or principlist ones, which do not consider the fetus as a person and, therefore, as patients with moral *status* independent of the pregnant woman, make possible behaviors that attempt against life, promote eugenic behaviors and intolerant of disability. These positions are far from the ontological one, in which the value of a person is neither accidental nor changeable, nor subject to the opinion of third parties.

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